

Submission No. 566
(Inq into better support for carers)
A.O.C. 9/7/08



**SUBMISSION BY CARERS WA TO THE HOUSE OF
REPRESENTATIVES INQUIRY INTO BETTER SUPPORT FOR CARERS**

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Clerk Assistant (Committees)
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
Parliament House
CANBERRA ACT 2600

1st July 2008

To the Clerk Assistant

Please find enclosed the CarersWA submission for the Parliamentary Inquiry into Better Support for Carers. An electronic copy of the submission was emailed on the 1st July 2008.

Any queries relating to this submission should be directed to:

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Yours faithfully

A handwritten signature in black ink, appearing to be 'Paul Coates', written over a horizontal line.

Paul Coates
Chief Executive Officer

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1. ABOUT CARERS WA

1.1 Carers WA is the peak body for Western Australia representing carers within the state. We are part of a network of Carers Associations which represent each State or Territory and which also includes Carers Australia, the national peak body, based in Canberra.

1.2 The Strategic vision of Carers WA is:

'A positive caring culture throughout Western Australia'

1.3 Our mission statement is:

'To achieve the best life opportunities for carers by leading change'

Carers WA fully endorse the submission from the national peak body, Carers Australia.

1.4 The submission of Carers WA is presented to address the following terms of reference of the Inquiry, namely:

- The role and contribution of carers and how this should be recognised
- The barriers to social and economic participation for carers
- The practical measures required to better support carers

The fourth of the terms of reference deals with strategies to assist carers to gain access to the same choices and opportunities as the wider community. This is addressed within our Executive Summary where specific recommendations are provided.

1.5 Any queries relating to this submission should be directed to Paul Coates via the following contact details:



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2. EXECUTIVE SUMMARY AND RECOMMENDATIONS

Caring is often a very positive experience for the individual providing the care and is certainly a highly positive contribution to the well being and cohesion of Australian society. The removal of the caring role would fundamentally undermine the social and economic fabric of communities and it is in the interest of any government to ensure that the negative impacts of caring are addressed. If they are not, the gradual decline within communities will generate significant and potentially irreversible failure in the political, social, economic and cultural systems of Australia. The following priority recommendations are derived from this submission:

2.1 Consideration should be given to developing and implementing unified national carers legislation to provide consistency and wider coverage for recognising carers.

2.2 In the absence of 2.1 above, State legislation which is already in place recognising the role and contribution of carers should be extended to cover all key sectors including health, Disabilities, Education, Transport, Housing, Private enterprise, Employment etc.

2.3 One central Federal government agency for carers to centralise funding, service and policy delivery should be established.

2.4 Affordable Housing policy and delivery of homes should recognise the role of carers and the type of housing (supported or otherwise) which could be provided to carers and care recipients with prioritisation given to those who have a caring role. Operational housing policies by providers should be set at a national level and ensure carers are recognised in allocations policy, arrears management, rental levels and design of affordable housing (to allow independence and privacy to the carer, as well as catering for the special needs of the care recipient).

2.5 Education policy and delivery should recognise the carer role of students and staff. This should be translated in practical terms by initiatives which include recognition of carers in teacher training curriculum and flexible education policies for young carers (e.g. attendance, homework, deadlines, support activities, on-line learning options etc.).

2.6 Transport policy and service delivery should recognise carers. This should include access and free travel vouchers for carers when accompanying a care recipient.

2.7 Employment policies and regulations should recognise carers (carer friendly and flexible workplace policies). The legislative and regulatory frameworks should be addressed to guarantee minimum employment rights and conditions for carers including flexible working and leave arrangements including access to unpaid leave. The provision of government grants to employers to support and introduce these measures should be considered and supported by a national campaign to raise awareness amongst employers.

2.8 A superannuation safety net for carers should be introduced to improve their financial future via a National Carer Superannuation scheme. Consideration should be given to a fundamental review to scope and develop such a scheme.

- 2.9 A national carer specific vocational education and training program should be designed and implemented to assist carers to enter or re-enter the workforce. The program should provide training opportunities for carers and recognise the practical experience gained from caring (e.g. caring roles as work experience and examination exemptions, where relevant, particularly in care related professions).
- 2.10 A national program should be introduced to provide state based 'one-stop' information centres specifically for carers supported by mobile services to cover rural and remote locations.
- 2.11 A nationally funded program should be introduced to promote respite as a health promotion initiative and develop a highly flexible system via a voucher system which can provide carers with options to choose and design their own forms of respite.
- 2.12 A nationally funded program should be introduced to meet the social support needs for carers with specific targeted funding for those in rural and remote locations.
- 2.13 The implementation of a recognised national carer's card to provide more access to subsidies for social activities.
- 2.14 Extension of the National Carer Counselling Program with more flexibility for the provision of emotional support to carers and specific funding to support mobile services for families in rural and remote communities.
- 2.15 A National funded carer skills program should be introduced to enable the carer to deliver more effective care; e.g. first aid courses, manual handling, caring at home.
- 2.16 A fundamental review of the carer allowance/bonus regime should be carried out. The review should seek to identify and introduce targeted benefits for those in a caring role including tax deductions and/or grants for home modifications and long term equipment hire. The existing schemes should be made recurrent and funded at levels commensurate with the costs of caring.
- 2.17 University and TAFE health curriculum should incorporate the needs and issues regarding carers within under-graduate and post-graduate degrees relating to Health (ie: nursing, medicine, occupational therapy, physiotherapy, psychology, social work, care assistance, psychiatry etc). The curriculum should encourage family inclusive practice methodology from the beginning of professional careers.
- 2.18 The system of assessments delivered by government agencies should be reviewed with the aim at developing a system whereby carer's needs are individually assessed. The assessments should be based on the each individual family's needs, issues, supports, ability to cope and concerns, as well as the needs etc of the care recipient. Each caring situation is individual and needs to be treated as such, rather than 'does this family tick the right boxes'.
- 2.19 The provision of age-appropriate residential facilities for younger people with profound disabilities should be made a priority for affordable housing policy and delivery.
- 2.20 Within health agencies a comprehensive care planning protocol needs to be conducted as soon as practicable, involving all members of the care recipients support network, and taking into account the needs and wishes of both the care recipient and the carer/s.

3. THE ROLE AND CONTRIBUTION OF CARERS IN SOCIETY AND HOW THIS SHOULD BE RECOGNISED

Defining care and hence the role of the carer

3.1 A definition of the word 'care' reveals the multiple aspects of the role and contribution of the carer. In the dictionary the definition includes love, object of worry or anxiety, keeping, protection, look out for, make provision, be concerned, have thought or regard, watch over and so on. This definition in its totality encapsulates the role of the carer who in simple terms provides support and help for the daily living of care recipients. It translates in many cases to hard, demanding and skilled work which requires substantial emotional and physical effort. In light of this the carer role should be recognised for what it is – a valuable and worthwhile activity that is equal to, and often more challenging, than the work of those who are not in a caring role.

Key messages from the statistics

3.2 The role and contribution of carers is reflected within the wealth of statistics and research that has been produced. Some of the key statistics related to Western Australia are outlined in this section but the overriding messages that can be gained from the statistics within these surveys are:

- Carers provided a significant contribution to the care of vulnerable West Australians in terms of the physical and emotional amount of care support, the scope of illnesses, disabilities and health issues covered and the time devoted on a daily basis
- A quarter of a million carers live in Western Australia and surveys indicate that over half of these provide care for most of their adult life. Many provide care during their childhood.
- The role of the carer covers the whole range of the illness and disability spectrum of both physical and mental illness conditions. As such the role of carers ranges enormously from pure hard physical labour (lifting, changing, care recipient hygiene etc.), unusually arduous domestic duties (e.g. frequent clothes and linen washing), to medical procedures (PEG feeds, medication delivery, resuscitation) and emotional and psychological support.
- Carers, often with no or limited formal training, perform the roles that health professionals may characterise as nursing, administering medication, counselling, advocacy, physiotherapy, occupational therapy etc. In short the role encompasses a whole range of nursing, clinical and therapeutic support as well as what health institutions would categorise as support services (catering, cleaning etc.)
- Despite this significant role in health care the West Australian benchmarking survey of 2006 indicated that only a quarter felt that they were included in the decision making on the assessment and provision of health services by their provider
- Medical and basic living support issues aside, carers fulfil the role of a social worker, advocate, educator and social support in arranging activities to ensure the care recipient gets the best quality of life possible, often to their own detriment.

“The study also shows the huge financial impact of caring. Almost half of all carers are not working in paid employment. Another one-in-five works part-time, and over a third of these admitted they have to take time off work as a result of their caring responsibilities”

Stollznow, 2004, p. 20

The facts and figures behind the key messages

3.3 There is a wealth of data available with regard to carers in West Australia and this can be made available if required. The source of the data ranges from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (Published 2005) and international research to various local research work on specific issues conducted within the state by academic institutions and CarersWA.

3.4 Of the estimated 2.6 million carers nationwide there are approximately 250,000 in West Australia. Various data are published on the monetary value that can be placed on this unpaid work with national estimates exceeding \$30billion and therefore the contribution in Western Australia is estimated to be over \$3billion. Carers are usually family members, but may be friends or neighbours. Demographically they are of all ages, from all cultural and socio-economic backgrounds and are spread across urban, rural and remote Western Australia in proportion to the population. One in six carers in Western Australia is a primary carer. Primary carers are those who routinely provide the majority of informal help with activities of daily living.

3.5 A benchmarking survey of carers published in 2006 in Western Australia showed that around four fifths are women, 5% are under 25 years of age, 31% are over 65 and 3% are over 80. The respondents revealed that West Australians provide a caring role for the whole spectrum of medical illnesses, conditions and disabilities ranging covering chronic illness, severe physical disabilities, mental illness and frailty. The profile of carers is summarised as follows:

Profile of WA Carers	
Gender	80%+ women
Age	5% under 25 and 31% over 65
Years Caring	55% have provided over 20 years caring
Hours caring per week	80% provide over 40 hours, 27% over 100 hours
Numbers cared for	25% provide care for more than one person
Who caring for	44% are mothers for children, 20% are women for spouse

3.6 Chronic diseases such as cardiovascular disease, cancer and respiratory disease increase with age and will place further burden on the health care system and ageing carers. Even for people with severe or profound disability, most of their care is provided by informal carers and in their own homes (abs, 1998). 84% of people aged over 65 years are living at home and supported by unpaid carers. These data are consistent with evidence that most Australians would prefer to remain in, be cared for and to die in their own homes (McCollum, 2002; Grande, Addington-hall and Todd, cited in Aoun et al 2005). For those living in rural and remote areas the availability of services usually accessible to Perth-based people is substantially reduced and adds to carer burden and stress, therefore placing an even greater emphasis on the role and contribution of the carer. The primary obstacle to obtaining services in rural and remote areas of Western Australia was the lack of their ready availability compounded by the great distances needed to travel to access them. For these carers the feeling and impact of isolation is far greater.

What WA government and associated legislation recognises

3.7 The role and contribution of carers has been recognised by the Parliament of Western Australia through the Carers Recognition Act 2004. The object of the Act is to recognise the role of carers in the community and to provide a mechanism for the involvement of carers in the provision of services that impact on carers and the role of carers. A Carers Charter within the Act outlines the following principles:

- Carers must be treated with respect and dignity.
- The role of carers must be recognised by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.
- The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.
- Complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.

Limitations of the recognition legislation

3.8 This legislative base provides an excellent starting point for recognising the role of carers and this is viewed positively by the caring community. It is however a start point rather than an end point. The Act is limited to Hospital and Health Services and the Disability Services Commission. The impact on carers in carrying out their role cuts across the whole lifetime of an individual so whilst health is an important issue for carers, it is only one aspect of where recognition, involvement and support are required. Young carers require recognition in education as they tend still to be in full-time education and the impact of the caring role adversely affects their learning and skills development and they lose out on out of school activities most take for granted. As the life cycle moves on to young adulthood the issue of training, skills and work becomes critical. Further along the life cycle issues such a child care and housing takes on a greater importance. To truly recognise the role and contribution of

carers, legislative instruments must recognise and cover all key areas of an individual's life including, but not necessarily limited to:

- Health and disabilities - Recognising involvement in care and service planning and delivery of care recipients throughout the health sector (hospitals, clinics, GPs etc). As well as acknowledging the need for greater access and priority to services in light of the health issues of carers caused by the caring role.
- Education – Institutions and teaching staff recognising the issues faced by children and students who are carers and the policies and service delivery of teaching allows for flexibility
- Employment – Employers in all sectors (public and private) recognising the issues faced by employees in a caring role and translating this into flexible workplace policies which accommodate the needs of carers whilst not compromising operational issues.
- Housing – Housing policy and delivery of public and affordable housing recognising and taking account of the needs of carers in terms of housing priority, allocation and design
- Transport – Transport policies, service delivery and pricing recognising the needs for carers who must accompany those being cared for.

Financial Contribution

3.9 As well as the physical and emotional commitment and contribution provided by carers the almost hidden financial contribution they make is significant. A study by Edith Cowan University in Western Australia on the out of pocket expenses for carers confirms the issues identified in national and international studies, that almost all carers had at least one out-of-pocket expense. Transportation and health care management were the most frequently identified items that incurred out-of-pocket expenses for carers. The items that incurred the most significant costs were agency services, modifications to the home, special equipment and special food.

3.10 Carers median gross personal income is significantly lower than that of non-carers and has long-term consequences for carers when they retire. When caregiving, national and international studies have shown that many carers struggle to pay bills and “non-essential” items such as holidays and leisure activities are beyond the reach of many carers. In addition, caregiving, including financial concerns, can impact carer's own health. Moreover, carers have little financial wherewithal to contribute to their own retirement due to current caregiving financial demands (Striking the Balance, 2005).

Conclusions with regard to the role and contribution of carers

3.11 The ageing population and the trend towards care in the community will increase the number of carers required to provide home-based care to Australia's chronically ill, disabled and aged. Therefore the economic and social reliance of Western Australia on the hidden contribution of carers will increase substantially. If this remains unrecognised in terms of practical help and support then society and the economy will become increasingly undermined.

3.13 The carer profile does include the whole range of society in terms of economic, social and cultural background but also includes the younger section of the community. This is of specific concern because the negative impacts of caring, if not addressed by the government, can adversely affect the whole life of a young person from their early education to fulfilling social and career aspirations. Young carers are part of Australia's future and the need to support them is paramount.

3.14 In the current systems carers are more likely to;

- become economically disadvantaged
- under-perform in the education system
- be unemployed
- have to make employment sacrifices, such as, reduced working hours, passing up promotion opportunities or taking additional leave
- to become ill and chronically ill
- to encounter poverty in old age

4. THE BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS, WITH A PARTICULAR FOCUS ON HELPING CARERS TO FIND AND/OR RETAIN EMPLOYMENT.

"It is a long-term, life-long commitment. The future is uncertain as we do not know if he will ever have independence or move away from home. Our life seems to revolve around our child...we must always consider him. In some ways it has made us stronger and more caring as individuals and closer as a family unit. I worry about the long-term prospects and the responsibility his sibling will have when I am no longer here." (Dyke et al, 2007, p. 41)

Carer identification and recognition - 'I'm not his carer, I'm his mother...'

4.1 Self-identification of the caring role and even the term 'carer' is one of the biggest barriers for family members and friends of people with care requirements. Essentially, many West Australians in caring roles will see their care responsibilities as an extension of the pre-existing relationship; be it parent, child, sibling, friend, spouse or other (Market Equity, 2002). Similarly, other family members and friends will often not identify this extension of the relationship, again seeing it as 'what you do'. Some comments from carers over the years have included:

- 'Mum looked after us as kids, now it's my turn to return the favour'
- 'We said 'til death do we part, and in sickness and in health...'
- 'He's my son...of course I am going to care for him'
- "She would have done it (cared) for me'.

4.2 All of the above points are valid observations, just as being a parent has its' validity. However, whilst most people are able to relate to the demands of being a parent, many cannot (or do not want to) relate to the demands of being a carer. The reality can be painful, uncomfortable and indicative of 'something being wrong'.

Workplace identification - 'Gee, Bob seems to take a lot of time out for his mum...':

4.3 As for the above, workplace attitudes can prove very difficult for working carers to overcome. There is a perception by people in caring roles that '...it is okay to come in late if you need to drop your child at school or attend assembly, but if I ask to take my mum to her appointments, it is different'. Whilst this comment is based on fact, it is indicative of a perceptual issue within the community and workplace that a caring role is somehow 'less than' a parenting role.

4.4 As a result, many working carers do not inform their line managers or colleagues that they have an ill or disabled family member for fear of being judged. Rather, they will use their Sick and Annual Leave entitlements to take time out, or, in some cases, will resign from their positions where the workplace is not flexible enough to cater for their individual circumstances. This then leads to financial and social difficulties. Many cases are now being put for Superannuation funds to be accessed early due to the costs of care and daily living that are not

covered by pension or benefits. This can have significant financial impacts on carers upon retirement.

Health and service staff

4.5 Research conducted in Western Australia by Bulsara (2006) stated that "...although GPs were largely aware of the issues around the difficulties with referral to services for carers, many were unable to assist carers in dealing with their own emotional problems. GPs generally referred them onto other formal services or prescribed anti-depressants and other medications as a means of dealing with carer stress. Many were unaware of the community services available for carers and often used prescribing of medications to carers rather than exploring other means of providing support." (p. 6).

4.6 The same could be said for hospital staff, specialists, pharmacists and the like, when it comes to identification of, and support for, carers. Whilst much of the communication and contact with patients will generally include their family carer, health and other staff having difficulty identifying the carer in their own right or that they may have support needs themselves. Some comments captured by Bulsara included:

Difficulties with the GP Practices

4.7 Some of the main difficulties are as follows:

- Getting through to receptionists is sometimes very difficult.
- Carers were asked to wait outside the surgery because their children (with a disability) making noise or being disruptive.
- Waiting lists are generally very long and sometimes it takes three weeks for an appointment.
- Not many doctors go to further away from city e.g. Kalamunda." (for home visits)

(Bulsara 2006)

Community understanding – 'It's amazing what they do...I couldn't do it!'

"Having a child with a disability has definitely changed the way we live in many ways. We most certainly would have lived a different life, had our daughter been normal. We may have travelled more...I may have entered the workforce...we really don't know."

Dyke et al, 2007, p. 41

4.8 In general, community understanding of the caring role, its' responsibilities and impacts are not very well understood. The impression that the general community has of carers tends to be paternalistic and glorified, seeing carers as selfless, saint like and out of the ordinary. People in caring roles just want to be recognised as ordinary people doing what anyone else would do for a loved one, and being supported accordingly.

Inflexible workplace: Lack of time flexibility - 'If I could start a bit later and finish a bit earlier sometimes...'

4.9 As for families with infants and school aged children, carers would like to have the recognition within the workplace of the additional responsibilities of caring for someone at home. There have been many anecdotal reports to Carers WA over the years by working carers who are viewed as 'lazy' or 'over-involved' in the care and support of their care recipient by their workplaces. Unpublished research papers into working carers of ageing parents and people with disabilities suggests that there is a lack of understanding by management and peers of the need for flexibility for working carers. (Butorac, 2006, Butorac and Gatley, 2008). Similar international research supports this.

Inflexible workplace: Capacity for Carers Leave - 'by the time I use my leave for medical appointments and missed respite, there's no time left for me. What if I get sick or need a break?'

My career – how can I ever return to full-time employment if I need to take Karina to appointments randomly, often and weekly or fortnightly intervals? Hence our family earning potential is drastically affected for the rest of our lives. The Super fund and financial security both X and I wanted has been curtailed".

Crofts, 2000, p. 59

4.10 As for 4.9 above, use of leave and flexibility in the workplace is of utmost importance to carers who are already working or considering returning to work. Butorac and Gatley (2008) found that:

"Understanding the dual working/caring role is a matter of importance. It is important to the carer and to society generally because it relates to the carer's ongoing involvement in work and the benefits it accrues – economically, socially and in terms of their own health and wellbeing. It is also important so that appropriate support services may be made available to the working carers and those they care for." (p. 4)

4.11 Carers are constantly worried about their own health and wellbeing. Those who have the dual role of working and caring shoulder additional financial burdens and concerns when they have to take unpaid leave due to their own or others' ill-health.

"Because a lot of caregivers have considerable high skill jobs, the loss of income due to unpaid leave is \$AU 14,434.20 on average." (Ruanjahn, 2006)

Inflexible workplace: Understanding workplace and co-workers - 'People just think I'm not pulling my weight'

4.12 Sleep deprivation from endless nights of interrupted sleep through caring responsibilities, worry, unforeseen medical and other emergencies all contribute to working carers not performing to usual expectations in the workplace. Many carers choose not to tell their employer the extent of their caring role due to the perception that they may be overlooked for promotion or seen to be unreliable. Whilst this perception may be incorrect in many cases, there have been instances of potentially discriminatory workplace practices based on working carers' responsibilities at home.

Inflexible and limited respite and support options - “We just don’t seem to fit into their guidelines or services”

4.13 The above statement is heard very often by frustrated, stressed and angry carers. Those whose care recipient is undiagnosed or has complex and compounding issues face particularly difficult situations, as do those caring for a person with a mental illness or who is resistant to services. Very often the service is based on the Instrumental Activities of Daily Living (IADL) of the care recipient, rather than the combined and complex nature of the caring relationship. In Western Australia, the Wellness approach in aged care and Person-centred planning in the disability sector is beginning to take family dynamics and coping into account, but there is still a long way to go. Carers own needs and issues need to be factored into service assessments much more. A carer’s own support network, life stage and ability to cope with a particular situation are interdependent with the functional needs of the care recipient.

Capacity of respite/support services and staff expertise - “I don’t know how many times we’ve tried to show (care worker) the best way to work with mum”

4.14 Particularly in the past few years of staff shortages, carers in WA are frustrated with:

- staff turnover (lack of consistency of care),
- not listening to the carers lived experience with the care recipient,
- staff being under-trained for their work,
- issues with Occupational Safety and Health (i.e.: where lifting and transferring are required, or medication / injections are involved), where the service does not provide such support, or incorrect or no equipment is available. Ruanjahn, 2006;

4.15 Where such services are unavailable, carers are unable to fulfil their paid working role, due to the lack of services available. Similarly, availability of appropriate and meaningful respite for the care recipient may be difficult to find on the days that a carer may be working. This is especially so for parents of children with disabilities who leave school upon completing year 12. Parents may have been able to work and access after school care whilst their child was in school, however, there can be significant difficulties in accessing meaningful full-time post-school options once their child has finished school. In WA, there have been many anecdotal cases of carers having to leave their work and take up full-time care due to the lack of available post-school options for their child. In some cases there have been reports of availability of a service on days that the carer is not at work, but not on days that they are contracted to work. This incompatibility has led to the carer having to resign from their work, which has financial, emotional and career-impacting ramifications.

“two issues are of my main concern (1) availability of housing funding for special needs people is appalling as is (2) going from full-time school to 2-3 days of post-school options is a (bad) joke”

WA carer, Carers WA Issues Survey, 2007

Prohibitive respite and support guidelines - “They’d give us overnight respite, but I have to visit at 9.00pm to give my daughter her insulin injection! How is that respite?”
(Complaint to Carers WA, 2005)

4.16 This is echoed in many research papers and issues reports, including Barratt (2005) who found that “Gaps in services included insufficient respite care including in-home respite and occasional or emergency respite for carers at the end of their tether. Some respondents singled out appropriate respite for aggressive patients and for disabled children as an identified need.” (p. 3)

4.17 Many barriers for carers in general relate to the availability and criteria for service provision, be it respite through to domestic help and personal care support. Whilst it is important for service agencies and government to provide support to those most in need, access to appropriate, meaningful and responsive supports for families may actually help to prevent the use of many crisis-based services and hospitalisation. This is not just for families where the caring role is extensive, but also for those who may benefit from a small amount of assistance at regular intervals. The role schools have in being a drain on a carer’s ability to work/ study needs to be raised here also. All carers (and service providers confirmed with case studies) that they had had to give up work and study opportunities as they had to be available to take their child from school if their child acted up or was sick in any way.

4.18 Carers WA hold workshops for carers and service providers alike. At one workshop for carers, one participant announced that she didn’t “...have a personal life. There are so many people here (in Perth) who know more about us than we do!” When asked what this meant, the participant replied “we’ve been assessed so many times, by so many services that I feel like a broken record and a beggar at the same time.” Other carers have continued to voice the very same message over the years. Some examples of assessments that a family may go through include (but is not inclusive of):

- Centrelink – Carer Payment
- Centrelink – Carer Allowance
- Transport
- GP
- Home and Community Care Services (Multiple Providers with own assessments)
- Carelink
- Companion Card
- ACAT
- Specialists (multiple)
- ACROD
- Carer Respite Centre (multiple times)

4.19 Many of the above service assessments may be conducted for each discreet service event, whilst others will be reviewed periodically. The amount of assessments for essentially the same illness/disability and situation is a barrier in itself. Many carers and care recipients have 'assessment fatigue' from the amount of hoops that they have to jump through – many just do not bother asking for help, knowing that they would have to go through the assessment process again. For some, it may be easier to stay home themselves and provide all of the care, rather than being assessed for a service that may not be available, or at a convenient time, or that is not meaningful for the care recipient.

4.20 A focus group held by FAHCSIA into the review of the Carer Payment (Child) in Western Australia reported that all carers in attendance "found the forms very un-user-friendly and cumbersome and that it wasn't easy for them to fill it out as a carer to qualify for Carers Payment (Child)". The same can be said for carers of people with a mental illness. This is echoed across many assessments.

Limited service options

4.21 As for the above comments, in Western Australia, with issues of workforce shortages and low pay for care workers (average of \$16-\$19p/hr), those who are asking for services currently may also have the disadvantage of not having the required services available. Whilst this is a national economic issue and not the fault of service organisations, it may have a significant impact on whether a carer returns or continues to work. Families living in rural and remote Western Australia are particularly affected by the staffing shortages and costs of living.

Lack of support and normalisation of caring role – "I'm trying my hardest, but it's all just too hard."

4.22 Many carers are of the misguided belief that they have to do everything required for the care recipient, and to ask for help is tantamount to acknowledging failure. Carer-identification is important as soon as possible, so that effective messages and support are provided to enable families to cope better for longer and access services sooner rather than at crisis point. A survey conducted in Western Australia by Ruanjahn (2006) found that "...approximately 40% of caregivers of working age are full-time caregivers, about 20% hold part-time jobs, and only less than 10% works full time." (p.1)

"I didn't marry to become a carer [laughs]! But I have got a husband with Parkinson's since sixteen years ago so caring for him has been a full time job."

(Bulsara, 2006, p.11)

Recognition of carer issues and competencies by employers

4.23 The problem of loss of confidence is now more recognised with regard to mothers who leave the workplace to bring up children. It is not, however, recognised for people who have been in a caring role for an extended period and therefore may suffer from a lack of confidence in their skills, knowledge and abilities. Many carers who have left the workforce to care have excellent education and experience, but having to leave their careers to care can set many people back in their confidence to return to high performance positions. Providing supportive,

flexible and realistic stepping stones for carers to return to the workforce through systematic induction and re-training is vital.

4.24 The nature of the role and responsibilities of the caring role provide well developed skills in crisis management, time management, organisational skills, communication at many levels, negotiation, multi-tasking and prioritisation among others. Carers and employers need to understand and acknowledge this.

Centrelink and other associated financial restrictions – “If I work more hours, I’ll lose the Health Care Card and rent assistance – I can’t afford that”.

4.25 The loss of ‘benefits’ and associated supports through working can be a significant barrier to carers returning to work or accepting more hours as they become available. With the increases in rent, interest rates and petrol, financial issues are of great concern to those on low and limited incomes. Returning to work can actually be a backward step financially for some families.

Carer guilt – “I shouldn’t be socialising – there’s work to be done”.

4.26 According to the ABS (2004), individual carers on average contribute 104 hours per week caring for a person with a mental illness, and 64 per cent of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation (ABS 2004). Similarly, Pakenham et al (2005) found that on average, carers spent 113.8 hours per week caring. The fact is that carers spend so much time caring that there may be no time left for them to even consider having a life of their own, let alone working!

Lack of awareness from the care recipient - ‘I don’t need respite! I’m fine’.

4.27 Lack of insight into the demands of caring by some care recipients can have significant impacts on carers receiving the support that they require. This is especially so with carers of people with mental illness (Pagnini, 2005) and frail aged where dementia may be a factor. There are also issues for families where their child has behavioural issues (i.e.; autism, ABI and behavioural/developmental disabilities) that make accessing external supports prohibitive.

Lack of service support to continue to manage care - ‘If I knew this then, things would be so much different...’

4.28 Many families are not provided with appropriate and timely information about supports that they can both access and rely upon until a crisis situation. A Carers WA survey in 2002 found that on average, carers found out about most services at least 5 years after initial diagnosis. This meant an average of 5 years coping alone, with little to no support or information about what was available to them within their own community. Services that they were aware of were primarily ‘formal’ services such as specialists.

Carer Health - “I have been getting headache and eye aches. I had two to care for, but one (my sister) died of brain tumour a few weeks ago”

4.29 It is fact that taking on a caring role significantly impacts on owns own morbidity and mortality. Cummins et al (2007) found that “The major reasons carers are not receiving

treatments for themselves is that they have no time or cannot afford the treatment” (p.24). This is in keeping with anecdotal accounts from carers attending workshops, counselling sessions and the like at Carers WA. Carers are also very concerned that if anything is wrong with them, then the care of others will be compromised. This places additional burden on carers to stay fit and healthy – neither of which are easy with financial, time and care commitments.

Future care requirements - “Who will look after him when I can’t”

4.30 Fear for the future care of a loved one – particularly for parents of children with a disability – is a worrying burden. Finding appropriate residential and other short-term respite is difficult enough, without the addition concern for securing long-term, meaningful care. Combined Application Processes (CAP) in WA are emotionally and psychologically damaging for families, who effectively have to say and prove that they are *falling* to provide their loved one with what they require. The lack of appropriate residential and non-residential care is a major factor for families not being able to return to employment.

“(Official policies) put tremendous pressure on us to cope, or be seen as failures as parents. We were at absolute rock bottom. But because we were financially sound, we were deemed to have no needs by all the authorities we sought help from.”

Crofts, 2000, p. 53

Disability and Marriage breakdown – “nearly one quarter of carer respondents were sole parent carers.” (Croft, 2000, p. 55)

4.31 Many sole parent carers attribute their marriage or relationship breakdowns to the ongoing, significant and often lifelong stresses of caring for a child with a disability. Without good support and information from the very beginning of diagnosis, many relationships fall apart due to the ongoing pressures, loss and grief issues and feelings of helplessness and hopelessness. Single parent families have associated financial and emotional difficulties, leading to even less likelihood of entry or re-entry in social and employment options.

4.32 The impact the above therefore has on establishing future sustainable security – employment, education, relationships, financial and housing - is profound.

5. PRACTICAL MEASURES REQUIRED TO BETTER SUPPORT CARERS

Wider recognition of carers

5.1 Although there is specific legislation for carer recognition in Western Australian this is limited and nationally there are a range of approaches. There are clearly various initiatives to include and recognise carers and these may range from representation within health networks to inclusion in local community access forums. Nevertheless this is sporadic and inconsistent across government sectors and public services. There is even inconsistency of approach across divisions within government departments. CarersWA would like to see the Federal government seriously take the lead in Carer Recognition

Recognition by normalising the caring role

5.2 Within Western Australia state legislation the health and disability departments are expected to include carers as partners of health professionals in care planning and to support carers own needs as a community and family member. Normalising caring also means providing basic and practical information at diagnosis and subsequent key milestones in the health delivery process. These milestones are very variable depending upon the health issues facing the care recipient but can include:

- the transition into adulthood for a child with a profound disability
- a deteriorating neurological condition
- an episodic mental illness
- an ageing parent experiencing increased care needs (from low to medium to high)

5.3 Those who deliver health and disability services should automatically include carers in the health delivery process throughout all stages and be required by regulation to provide basic and practical information at all key stages of the health care process

“My GP has opened the door to my being involved and I have found this invaluable because my son’s condition is very complex. He [GP] was very positive and it really helped me gain direction. He also referred me on for counselling services and signed this for me.”

(Bulsara, 2006 p. 9)

Addressing the information needs of carers

5.4 There remains a multiplicity of agencies and services that provide information which can present a confusing, off-putting and impenetrable process for carers. The Carelink centre concept does not respond to the information needs of carers as it was designed to meet the needs of a variety of target groups. The need for information can be best met in the form of a one stop shop dedicated to carers in which the multiplicity of service providers, health professionals and others can be linked. In addition many carers do not respond well to call centres and phone services only and would prefer a person centred face to face model of service delivery. The location of information centres for carers has to be addressed as it is not meeting carer’s needs. The information needs of carers would be best met in a variety of central

settings such as information centre for family carers in every teaching hospital, local community centre and Centrelink offices.

Respite provided flexibly and as a health promotion measure

5.5 Although significant government funding and service delivery effort is expended in the area of respite, the models of delivery and provision are insufficiently flexible to address the need of many carers in the context of their life circumstances. Respite must be promoted and delivered as a health promotion measure rather than a fixed service if it is to help prevent carer burn out and contribute to the health and wellbeing of family units. Provided in a flexible way, respite can help to underpin family relationships and maintain the family as a functional unit. To do this the rules and regulations for qualifying for and utilising respite must be far more flexible and open. Respite could mean separation of the care recipient from the family as provided in the traditional model but, equally, it could mean the chance for the whole family (including the care recipient) to have a holiday and change of scenery. It could also mean that support is given to perform the household chores whilst the family spends quality time together. In short, respite could mean a whole range of support initiatives not currently covered by the existing regulations and service delivery regimes. Ultimate flexibility could be provided by, for example, a voucher system which allows families to choose their own form of respite which suits their specific life circumstances and the needs of the care recipient. The usage of the voucher could include respite in order to continue in the workforce, to holiday with family unit, the use of day centres, residential respite as transitional solution for planning of long term care, foster families and/or employment of own care worker on needs base.

The social participation of carers

5.6 According to the Carers WA survey (Nov 2007), one of the key issue for carers still is the social isolation and diminished social interaction for carers. Social isolation is one of the common negative side effects of caring over a long period of time. The reasons for isolation and the lack of social interaction include

- lack of financial means to engage in social activities
- lack of time and/or flexible respite options
- the discontinuation of friendships due to carer commitments
- geographical factors

5.7 Support groups in local areas working in collaboration with respite and/or day centres is one of the practical ways in which social isolation could be addressed. Existing resources could be exploited such as the use of community centres to organise and run support groups in the form of activity groups. Additional resources are required to

- support the individual carer to enable them to participate in local social events, and
- set up, staff, run and organise specific community events

5.8 Generic funding for these events is required and is of particular value in rural and remote communities. For the carers themselves the provision of specific financial support to enable them to attend and participate (to pay for respite etc.) would be of great benefit. This could be provided through a mechanism such as a national carer's card.

5.9 In establishing support mechanisms and events it is important to realise that carers often do not self identify and that those who do self identify do not want to be singled out as a specific group. Rather than have catch-all carer specific planned activities these should run according to issues and interests that cut across the whole community i.e. gender, age and culture. Special attention should also be given to the social support needs of younger carers to assist the development of social and communication skills for their adult life.

Addressing the emotional support needs of carers

5.11 Ongoing emotional support to carers and their families by well trained counsellors is one of the key aspects of supporting carer's emotional health and wellbeing and preventing carer burn out. The National Carer Counselling Program is one of the successful programs offered to carers addressing those emotional needs in times of distress and crisis. The continuing and extension of this program is vital in supporting carers in their caring role. The impact of caring can potentially adversely affect any aspects of life (social, financial, relationships etc.) and breakdowns are not always evident as directly attributable to the caring role.

5.12 Also, counselling and support can be provided in many forms, different models of support may be more effective for individuals in certain circumstances or of a different mindset. The guidelines for the National Carers Counselling Program are relatively limited and should allow more flexibility in the way emotional support is being delivered (e.g. e-mail counselling, art therapy and couple/relationship counselling). In Western Australia there is a significant population spread over a large geographical area. To provide effective support specific funding for mobile services is particularly important.

Providing training opportunities to carers

5.13 It is of paramount importance that the role of carers in the public health system is recognised. They are significantly involved in the clinical processes including recovery and rehabilitation as well as the ongoing care of people with long term and, in some cases terminal, health issues. Most carers are not trained in basic nursing care when taking the care recipient home with the best of intentions. Families have to be recognised by health professionals as members of the care team and basic training is required in order to support carers adequately and therefore provide the care recipient with the best quality of life possible. Courses such as training in manual handling / Manutension at home assist in maintaining the carer's physical well being as well as the safety of the care recipient. Equally, the carer can be more effective with the support of general training in areas such as:

- basic first aid
- emergency care planning
- transition into care

5.14 The delivery of alternative training mediums is vital to enable penetration into rural and remote areas e.g. e-learning, video conferencing media etc.

5.15 Similarly, the ability to manage the caring role itself is of significant importance. Of all interventions and supports available, psycho-education for carers has consistently proven to be

one of the most effective supports for carers, providing them not only with accurate information, but allowing them to share their stories, what works for them and socialising at the same time. Such intervention has ongoing positive flow-on effects such as formation of support networks, skill development and expansion and respite in a non-confrontational environment.

Financial needs of carers

5.16 For the majority of carers caring comes not only at an emotional, physical but also financial cost. In most cases the income is diminished due to reduced working hours or exit from the workforce in order to take up the caring role. Often home modifications are required; special equipments hired or bought; special dietary needs met; medication and/or nappies for the care recipient needed. The reduced income in the form of a carer payment (plus allowance) does not go far in the caring situation. The carer loses also any additional superannuation contributions and paid sick or annual leave benefits during the time caring at home. Too many carers have to rely on charities in order to get by. Additional financial support measures are urgently needed to support carers in their caring role including a review of current carer payment and allowance and a basic superannuation safety net for carers introduced. Other measures could include tax deductions for home modifications and for long term hire of equipment.

5.17 Financial support can also come in a step by step re-introduction into the workforce, with training and skill development offered at reduced rates or other incentives. Studies have identified that almost half of carers of working age do want to be part of the workforce, while they are in a caring role or after their caring role has ended. However, re-entry workforce training for former carers is limited and they often face age and wage discrimination when trying to regain paid employment.

Providing skill development options for carers to re-enter the workforce

5.18 Carers have the right to pursue their own interests and ambitions and a key element of this is met within the workplace. Employment brings a sense of worth and provides the financial means to carry on their lives and provide for others. The rapidly aging population and shortage of skills and labour in Western Australia is also well documented. Carers by the nature of their role acquire a range of skills which may be of direct value in specific professions. Training and skill development for carers who are planning to re-enter the workforce after a long period of caring is vital to assist in transitioning back into the workforce. This support exists for sole-parents and could be applied in similar form to carers on the carer payment.

The need for accredited and quality services

5.19 Carers require quality services for the person they are caring for. The quality of services affects all family members at all stages of caring while accessing respite or day centres, special need schools, accommodation for people with mental illness and the lack of services linked to the transition into adulthood, lack of mental health services and young people in nursing homes. Carers want to have a say and be involved and consulted in the planning and delivering of services.

Securing and maintaining a home

5.20 The population of Western Australia is projected to increase by one third over the next 20 years which will require up to 380,000 new homes. The scale of demand will put significant pressure on homebuyer affordability and the housing sector generally. With the inflating property market, affordability is already a significant issue for Western Australians and as the population grows so will the number of households that require support to cope with establishing and maintaining a home. In addition to affordability issues there will be economic, environmental and social sustainability issues as well as the need to develop the infrastructure to service the growth in homes. Even though food and shelter are considered by all to be fundamental requirements for a safe and secure life, the financial pressures placed on many of those in a caring role can jeopardise their ability to meet these basic needs. The provision of housing must be placed high on the agenda at Federal and State level and measures introduced to address what will become a fundamental and critical issue. Reliance on existing stock and existing initiatives is no longer an option and new and effective forms of interventions are required. In developing new initiatives it is self evident that the responsibility for creating a better and sustainable housing system cannot rest with the State Government alone and there will be a continuing and increasing need to form partnerships across Government and with stakeholders in the housing sector including the private construction industry. The vulnerability of carers must be recognised and introduced into affordable housing policy and delivery through a range of initiatives including:

- giving priority to carers in the development and provision of affordable housing
- designing homes to meet the needs of carers recognising the requirement for the special needs of many care recipients and ensuring privacy for the carer and care recipient who are often individual adults living under the same roof
- establishing operational processes that prioritise carers and take account of their circumstances (allocations policy, arrears management processes, rental levels)

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